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ABSTRACT

Developed as part of Delta College's Parent Awareness Program, this manual provides information related to the special concerns of parents and families of developmentally disabled children, adolescents, and adults. The first section stresses the importance of planning and preparing for the future and establishing adequate financial and personal resources. Questions raised by parents about issues such as friendships, dating, sex education, marriage, career possibilities, and alternative living arrangements are discussed; and the feelings and concerns of brothers and sisters of handicapped siblings are explored. Financial and educational issues are the focus of the next section, which presents information on supplemental security income, guardianship, and alternatives to guardianship (e.g., family and friends, citizen advocacy, trust funds, power of attorney, and limited bank accounts). This section also looks at the legal basis for special education, and the functions of individualized educational planning committees. A section on advocacy services for developmentally disabled citizens provides information on the Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc., followed by a paper entitled "A Practical Guide to Advocacy," by Mary L. Hines. The next section stresses the importance of developing social skills in the process of normalization. This section considers issues related to social acceptance, physical appearance, social coping behavior, self-fulfillment, assertiveness, dating, marriage, and sexuality. The final sections look at living and working alternatives for the developmentally disabled, examining group and nursing homes, state institutions, adult activity programs, and work activity programs. Each section includes references. (EJV)

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Delta College Parent Awareness
Lifetime Planning Manual
1984 - 1985

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* * * LIFETIME PLANNING MANUAL * * *

PARENT AWARENESS PROGRAM

Program For Parents/Families of
Developmentally Disabled Children, Adolescents, and Adults

1984 - 1985

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NORMALIZATION

A disabled child or adult should be helped to live as normal a life as possible. This concept of "normalization" first developed in the Scandinavian countries and was later transmitted to the United States primarily through the efforts of N. E. Bank-Mikkelson and Bengt Nirje.

Nirje refers to normalization as:

"Making available to all mentally retarded people patterns of life and conditions of everday living which are as close as possible to the regular circumstances and ways of life in their society.

Normalization means...a normal rhythm of the day.
Normalization means...a normal rhythm of the week.
Normalization means...a normal rhythm of the year.
Normalization means...normal developmental experiences of the life cycle.
Normalization means...having a range of chances, wishes, and desires respected and considered.
[illegible] ization means...living in a world made of two sexes.
No[illegible]lization means...the right to normal economic standards.
Normalization means...living in normal housing in a normal neighborhood."

Bengt Nirje

SPECIAL CONCERNS FOR THE FAMILY

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Sections on Concerns of Parents
and Special Concerns of Brothers and Sisters
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SPECIAL CONCERNS FOR THE FAMILY

Parents of disabled persons face intensive and sometimes long-range concerns. They become competent observers of their children in order to provide sufficient and timely responses. Their assumptions and attitudes about the disabled child influences their reactions and responses to, not only the disabled child, but also to their other children and family members.

As the disabled child grows older, parents also must influence others who come in contact with the growing individual. Often the severity of parents responses are dependent on how severe the child's disability is. Sometimes misdiagnosis or misinformation from professionals may confuse and embitter parents to the point of questioning the care and future of their child. Additional special care may bring about added expenses and sometimes financial problems. As parents age, their concern for continuing quality care for their disabled child increases.

"When the parents consider their child's disability a challenge, they are able to plan for personal value and role reorganization as their child grows from infancy to childhood and then adulthood. They are able to alter their expectations and behavior in furtherance of the developmental needs of their child."

"Parenting requires continued hope; consolation, when needed; facts, as appropriate; and acceptance of parental and sibling feelings. Even in the best of times, repeated crises may arise that would be helped by an empathetic counselor." (Focus on the Retarded Adult, 1980)

Growing up with a disabled family member requires support from relatives, neighbors, services and other concerned individuals.

Preparing for the future and establishing adequate resources helps to ease the transitions from infancy, to childhood, to adolescence, to adulthood.

These life support systems can help keep things going when things become overwhelming.

"...respite care services are springing up offering temporary care of the person with a disability so that the rest of the family is allowed time to relax, freedom to socialize, relief from the daily routine. Using experienced caregivers provides a benefit to the child with a disability as well. It affords the child a chance to grow, an opportunity to learn trust in someone outside of his immediate family members." (Practical Advice to Parents)

Joining a local parent group can offer a unique kind of understanding as well as strength and support to help accomplish needed changes in your community. Many services for handicapped children and adults, such as preschools, camps, education and job training programs were originally started by parent groups.

By planning for your child's future you can help him/her reach maximum physical, emotional and social development.

Concerns of Parents

As a son or daughter approaches the teenage years, parents are faced with the dilemma of whether or not their son or daughter will have friends. A parent may fear that non-handicapped friends may take advantage of or feel sorry for their son or daughter. A second concern for parents is whether or not their son or daughter will behave appropriately in a variety of social settings. Along with friendships, is the question

of dating. A disabled teenager may be interested in, and have a desire to date another teenager in their classroom or school. One way that parents may be able to work through this concern is to talk with other disabled teenagers and adults as well as their parents to see what solutions others have come up with. A parent may set up their own informal program of providing their son or daughter with a variety of social opportunities such as eating out, attending movies, wedding receptions, dances, etc. with both disabled and non-disabled persons. Each activity can be viewed as a chance to teach interaction skills which will be used by a son or daughter throughout life. A parent would be wise to fade out of the picture and allow attendance of activities without their presence to encourage independence of the disabled individual.

A third concern of parents may be the concern of sex education. As every individual approaches adulthood the interest in the opposite sex increases. If a son or daughter has limited verbal skills, a parent may be faced with how to explain this sensitive topic to a teenager. The parent must also be concerned with the thought of an unwanted pregnancy occurring. Many fine books are available for the disabled and their parents to explain sexuality to the disabled teenager. The parent must recognize that the teenager must be prepared to be responsible in his sexual activity or appropriate expression of sexual feelings. Parents need to keep in mind that when an individual reaches the age of majority a son or daughter may make certain decisions without parental approval. (refer to information on sexuality page 55)

Marriage of the disabled is another concern expressed by parents of the disabled. Parents often wonder if their son or daughter will

be able to succeed in a marriage to another person who may be handicapped also, as well as preparing their child for the responsibilities of marriage. Parents need to keep an open mind concerning a son or daughter's life choices and encourage the maximum amount of self-sufficiency possible for the disabled adult. The best rule for parents is: "Never do something for a person that they can do for themselves."

Many parents are concerned about career possibilities for their disabled child. Studies have shown that attitudes toward work and social skills are larger determiners in job success than a person's I.Q. score. A disabled son or daughter may receive vocational training that prepares them for a job, however, if punctuality and reliability are new to an individual he may fail to keep a job. Another consideration for families of the disabled individual who may never gain a driver's license is mobility training. Use of public transit systems, are a big step to independence that a family may assist in that will greatly expand career opportunities.

As a disabled person grows older the concern for living arrangements grows. The concern for living somewhere other than the family home may come first from the disabled person as they see brothers and sisters leave home. Parents may first notice some behavior problems and later the question may come "Why do I live at home when Sue has her own apartment?" A concern for the parent may be "What will happen to my son/daugther after I am gone?" Many times group homes and foster care homes and what they are like are unknown to parents. A first step for parents may be to talk with a licensed foster care provider, through the Department of Social Services. The family may want to visit a potential home

with their son or daughter before a time of illness, death or other crisis situation. Group homes or other living opportunities, generally welcome family involvement and visits if the family would decide upon this option. For a full continuum of living arrangements, see the module in this manual.

Special Concerns of Brothers and Sisters

As Bette Ross points out in a section in her book entitled Our Special Child, siblings have needs, too. Parents often are told that the brothers and sisters will be damaged by the inordinate amount of time necessary to raise a handicapped child. Although the "other child" does have some problems that are unique, a parent need not become overly concerned, just sensitive to these special problems.

As a disabled person approaches adolescence often his/her brothers or sisters are in the same age range. Adolescents become overly sensitive to physical differences and become attuned to peer pressure. Often brothers and sisters feel extremely embarrassed and would like to pretend that the disabled individual is not a part of their family. At other times a brother or sister may jump to the defense of the disabled brother/sister. At times a brother or sister may resent responsibilities connected with the disabled individual or have a tendency to do things for a brother or sister that they may be able to do for themselves.

Some suggestions for parents who are raising a family that includes a handicapped individual are outlined best by Bette Ross, and are as follows:

> "By being aware of some of the conflicts felt by brothers and sisters of handicapped youngsters, parents can help them to become more accepting and more understanding. Parents can:
>
> - have special times with each child separately...

- realize that to each of your children, his own life is the most important...

- not saddle siblings with responsibility for baby-sitting their disabled brother or sister all the time, but let them share the care

As parents develop their own positive habits, they may want to:

- gently encourage questions about the child's disability, if the sibling is old enough but not asking

- try to be aware that in plunging wholeheartedly into helping your afflicted child you aren't forgetting needs of others

- share as much information about the disability as the sibling can comprehend

- spread around your activities to include those important to the other children, too, such as being room mother at school

- frequently show your appreciation of the brothers and sisters, their help and their understanding."

"...the happy truth is that growing up with a handicapped person brings rewards of deeper maturity, greater compassion toward all handicapped persons and an almost spiritual affinity for nature's weak--in sum, a deeper, richer personality for the sibling." (Taken from: Our Special Child, Bette M. Ross)

Brothers or sisters are also concerned about a handicapped siblings future. The parent must be very careful to avoid making the assumption that John will care for his brother after they are gone. The future living or working alternatives need to be discussed openly with all the members of a family. Alternatives must be presented and weighed and discussed long before the family is facing a decision. A lifetime planning consideration, such as immediate direct placement in work activity centers or group homes, for disabled persons need to be planned ahead of time. Many Community Mental Health's throughout Michigan report at least a year's waiting list for entering this type of programming. Parents need to be considerate of all their children and young adults with needs, ambitions and limitations of their own.

Provide ample opportunities for all family members to express their feelings in an open and accepting atmosphere. A parent needs to keep in mind that he may not always agree with his children but that listening is a key to a happy and healthy family.

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FINANCIAL AND EDUCATIONAL CONCERNS

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Supplemental Security Income (SSI)

The SSI program combines federal and state funds to provide eligible disabled persons with a source of income. The income is intended to assist the individual in meeting some of the basic costs of everyday living--food, shelter and clothing. Additionally, and more importantly for some individuals, SSI services--Medicaid, Home Help Services (formerly known as Chore Services), transportation and day programs.

It is important to understand that SSI is a flat-rate program of assistance. While intended to meet the total living expenses for its recipients, the fact is, SSI is the sole source of funds for many recipients who are attempting to meet basic living expenses on an income which is substantially below the federally established poverty level.

Introduction to Supplemental Security Income (SSI) and Social Security Benefits (SSB)

Supplemental Security Income (SSI) and Social Security Benefits (SSB) are both administered by the Social Security Administration (SSA). They are two different programs. SSI is an income maintenance program for disabled, blind and aged individuals which is based on need, while Social Security Benefits are social insurance programs.

Any discussion about Supplemental Security Income would be incomplete without distinguishing it from Social Security Benefits and without saying a few things about Social Security itself.

A handicapped individual may receive Social Security (green colored check) in one of two ways.

1. An individual may receive Social Security Benefits from his/her own work account. If a handicapped person had worked and FICA was withheld from his/her check for the required number of quarters, that person might be eligible for, or may be receiving, Social Security Benefits.

2. A handicapped individual may be receiving, may be eligible for, or may be eligible in the future for Social Security Benefits based on his/her parent's Social Security work account. A surviving minor may receive Social Security Benefits if his/her parent, who had established a work account is deceased, retired, or disabled. In addition, an adult child disabled before the age of 22 may receive benefits on his/her parent's work account if that account has opened because of the parent's death, retirement or disability. The amount of the benefit is determined by the earnings of the person who established the work account, whether a beneficiary draws on his/her own or someone else's account, and by the number of persons drawing on the open account.

A Social Security benefit check arrives on the third day of the month and is meant to cover the previous month. For example, the check which arrives on November 3 is meant to cover the month of October and will be referred to as the October benefit.

A disabled person who receives Social Security Benefits but still meets the SSI income and resource requirements may be eligible for both Social Security Benefits and SSI. However, the Social Security Benefit will cause a reduction in the SSI payment amount. The SSI check arrives on the first day of the month (earlier if the first falls on a weekend or holiday) and is meant to cover that month.

The SSI and Medicaid (MA) programs were established by Titles XVI and XIX of the Social Security Act, respectively. FICA wage deductions DO NOT support these programs as they do in the regular Social Security Benefits which include Retirement, Survivors, Disability and Health Insurance (RSDHI) Programs. Rather, yearly Congressional appropriations provide most of the money for the SSI and MA programs. Some states, including Michigan, supplement the federal SSI payment amount. In nearly all states (not Arizona), SSI eligibility also indicates eligibility for Medicaid Benefits which are administered by the Deparment of Social Services or the equivalent department in other states. The gold colored SSI check, received monthly includes both federal and state contributions. SSI check amounts vary from state to state, depending on the level of

supplementation which has been provided by the particular state. Check levels vary in Michigan depending on an individual's income, resources and his/her living circumstances.

SSI (as well as Medicaid) is a program based in part on financial eligibility. Social Security and Medicare are not. Except for earnings above an amount established yearly by the Social Security Administration. Income and resources are not considered when determining eligibility, or benefit amounts for Social Security. However, income and resources, or the lack of them, are an integral part of the eligibility determinations for Supplemental Security Income.

Understanding the distinctions between SSI and Social Security Benefits is important especially because both are administered by the Social Security Administration, as is Medicare. To further complicate the issues, many people receive checks from both SSI and SSB programs. Additionally, a determination of disability for Social Security purposes is binding for the SSI disability determination. The opposite is not true. Determination of Disability for SSI is not a determination for Social Security purposes, even though the same criteria and guidelines are used, and the same agency makes the determinations.

Based on presumptive disability, (that is, where the SSA Claim Representative has no doubt that an individual is disabled), an SSI applicant will be required by SSA to apply for all other benefits, including Social Security Benefits, for which SSA believes the applicant may be eligible. (Taken from: Supplemental Security Income: An Advocates Manual, Association for Retarded Citizens/Michigan, 313 S. Washington Square, Third Floor, Lansing, MI 48933 (517) 487-5426, Revised Third Edition, June 1984)

Guardianship

"Guardianship is a legally authorized relationship between a competent adult (the guardian) and a minor child or handicapped adult (the ward). In this relationship, the guardian is given the duty and right to act on behalf of the ward in making certain decisions affecting the ward's life. When a guardian is appointed the court gives the guardian the authority to exercise certain legal rights of the ward in the ward's best interest. When a guardianship order gives certain rights to the guardian, it correspondingly takes those away from the ward. For this reason, guardianship is a very restrictive procedure and should only be used when necessary.

Alternatives to Guardianship

Most developmentally disabled people are able to manage their own personal and financial affairs without intervention of a guardian and with appropriate services and support from family and friends. Therefore, it is very important to explore less restrictive safeguards before considering guardianship. Several alternatives which might be appropriate are discussed below. This list is not meant to be exhaustive and it is important to realize that the various guardianship alternatives can be combined to meet the unique needs of the individual.

Family and Friends:

Most people consult with family members and friends before making important decisions or before making decisions in situations they are unfamiliar with. Developmentally disabled persons are no different. Family members and friends can provide much guidance and support to a developmentally disabled individual

and can preclude the need for a guardian. For instance, family members can help define risks, advantages and consequences of a decision and explain these in terms the disabled individual can understand. This provides a basis for the developmentally disabled individual to make his/her own choice.

Citizen Advocacy:

Citizen advocacy is a program in which trained volunteers are matched with individuals who are mentally retarded or otherwise developmentally disabled. The relationship is similar in many ways to the "Big Brother/Big Sister" program. A citizen advocate may assume a wide variety of roles depending on the needs of the individual who has the disability. Citizen advocates can serve as guides and advisors, may assist with budgeting and paying bills, may help make purchases, and may perform any of the supportive activities that can be done by family and friends when they are present. Citizen advocacy programs are operated through a number of local Associations for Retarded Citizens in Michigan.

Trust Funds:

A trust is a legal device which permits a person or institution (like a bank) to manage the property and money of another person. If the reason for considering guardianship is primarily financial, a trust can provide a good alternative. The success of a trust depends on how the trust is drawn up and who is chosen as the trustee. If properly drawn up, a trust allows parents to place property or money in the trust to be managed and used for the benefit of the developmentally disabled individual. Since the developmentally disabled individual does not

own the contents of the trust, the trust will not cause the individual to become ineligible for governmental benefits such as Supplemental Security Income (SSI). Furthermore, the government cannot seize the contents of the trust as repayment for past benefits. On the other hand, interest from the trust can be used by the trustee to purchase goods or services for the ward wich are not covered by government benefits. There are many different types of trusts (living trust, testamentary trust, revocable trust, irrevocable trust, insurance trust, etc.). Within each of these types of trusts there is great variety depending on the terms of the trust. Although a trust does not give the trustee power to make personal decisions for the developmentally disabled individual, parents could specify in the terms of the trust that the trustee will act as an advisor to the beneficiary (developmentally disabled person) in making certain personal decisions.

Trusts are complex and it is important to seek the assistance of an attorney. Before seeking legal assistance it is a good idea to carefully analyze what you want the trust to accomplish.

Power of Attorney:

Any individual can give someone else the power to make decisions regarding his/her estate. The person given power of attorney has only that power (those powers) given him/her by the individual who is developmentally disabled. Power of attorney may only be used if the developmentally disabled individual fully understands what it is that he/she is authorizing another individual to do.

Limited Bank Accounts:

There are several ways in which access to finances can be voluntarily restricted through specialized bank accounts. (Please note that not all banks are agreeable to establishing these types of accounts.)

Some banks will set up accounts in which two or more persons must sign to authorize withdrawals. Neither person could withdraw funds without the knowledge and approval of the other. The account could be either a checking or savings account.

Ceiling Limit Account:

Another alternative might be a ceiling limit account established in the name of the developmentally disabled person. Using this method the individual would be able to withdraw only a limited amount. Checks or withdrawals over the specified amount would be invalid.

Pour-Over Account:

The pour-over account is a second account which automatically transfers money to the limited account after a withdrawal so that

a limited amount is maintained. The amount of each withdrawal is limited but the individual always has access to the specified amount of money.

Representative Payee:

If the only income an individual has is SSI, social security or some other federal supplement, a representative payee may be an appropriate alternative to guardianship. A representative payee is an individual who is given the authority by the Social Security office to receive and manage federal benefits for another person deemed unable to manage his/her own money. Application must be made to the Social Security Administration to be appointed a representative payee. Local social security offices can provide information regarding application.

When guardianship is necessary

Legislature has reaffirmed that most developmentally disabled people are able to effectively manage their own affairs without intervention of a guardian. Guardianship may be used only when a court determines a person to be incapable of managing some, or all, of his/her affairs. Further, guardianship is intended to be used "only as is necessary to promote and protect the well-being of the person." If guardianship is necessary, it should be utilized to encourage the development of maximum self-reliance and independence in the individual. Therefore, the issue of guardianship should not be approached lightly."

Types of Guardianship

"Since the capabilities and needs of individuals who are developmentally disabled may vary greatly, the Michigan Legislature provided

for flexibility in the guardianship statute. There are two basic types of guardianship duties: duties pertaining to the person and those pertaining to the estate. Some individuals may require a guardian who has responsibility for both the person and the estate.

Most importantly, the statute allows for different degrees of guardianship. Guardianship may be partial, giving only specifically described powers to the guardian, or guardianship may be plenary (total or full). This means a person could have a partial or plenary guardian of the person and/or a partial plenary guardian of the estate.

Guardianship of the Person

A guardian with power over the person refers to the individual appointed by the probate court to have legal rights and powers of personal decision-making over the ward. A probate court may authorize a guardian to assume some (partial guardian) or all (plenary guardian) of the following responsibilities for the ward:

1. "Custody of the ward." The question is charged with supervising the ward's personal needs by seeing to it that the ward is properly housed,* educated, and generally cared for. This does not mean the guardian must take the ward into his/her home, merely that the guardian ensure the ward's needs are met.

2. "The duty to make provision from the ward's estate or other sources, for the ward's care and comfort, and maintenance." Simply stated, the guardian is not responsible for providing all of these essentials to the ward; only with ensuring that they are being received by the ward. One implication of this duty is that the guardian has the responsibility to make application for any financial benefits for which the ward may be eligible.

3. "The duty to make a reasonable effort to secure for the ward training, education, medical, and psychological services, and social and vocational opportunity as are appropriate and as will assist the ward in the development of maximum self-reliance and independence." This does not mean that the

* The probate court must approve placement of the ward in a facility (MCLA 330.1623). The guardian has the duty to notify the court if the placement is inappropriate.

guardian must purchase services for the ward. It means the guardian must apply for services and benefits for which the ward is likely to be eligible. Subsequent modules will describe these services.

Guardianship of the Estate

A guardian with power over the estate refers to the individual authorized by a probate court to assume responsibility for the management of all or some of the individual ward's property. The ward's property may include personal income, stocks, bonds, certificates of deposit, real estate or other assets. The guardian who has power over the estate should never commingle the ward's funds or assets with his/her own funds. The court requires an accurate and detailed accounting of financial transactions made on behalf of the ward.

Guardian Ad Litem

After a petition for the appointment of a guardian has been filed, a probate court may determine that the proposed ward needs a person to represent his/her best interests and to assist legal counsel. If this is the case, the court may appoint an interested person or entity to serve as guardian ad litem. The duties of the guardian ad litem are limited to the pending legal action. Authority of the guardian ad litem ends with the resolution of the action. Payment for the services of a guardian ad litem may be required from the ward's estate.

Although payment for the services of a guardian ad litem may be requested from the ward's estate, the ward can file an affidavit of indigency (inability to pay) with the court. If the ward receives any form of public assistance, the court must waive the fees and costs upon filing of such an affidavit.

Temporary Guardian

A person who is developmentally disabled may require protection of a guardian before the guardianship appointment process is completed or when some action in relation to the appointment (i.e., an appeal) is pending. In either case, a court may opt to exercise the powers of a guardian or to appoint a temporary guardian. The temporary guardian's powers and duties must be specifically enumerated by court order. In the event a court acts as guardian itself or appoints a temporary guardian, a hearing must be held within 14 days to address the petition or to determine the need for the temporary guardianship to continue until the pending action is resolved.

Standby Guardian

A standby guardian may be appointed at the same time as the original guardian. The standby guardian agrees to assume the duties of the original guardian in the event of the incapacity, death or resignation of the initial guardian. In an emergency situation where the initially appointed guardian is absent and unavailable, the standby guardian may temporarily assume the duties of the original guardian.

Testamentary Guardian

Michigan law outlines two situations in which a guardian may be appointed by the parent of a developmentally disabled person through that parent's will.

First, the surviving parent of a developmentally disabled minor (for whom a guardian has not been appointed) may, by will, appoint a guardian to assume his/her duties as a parent upon that

parent's death. The testamentary guardianship becomes effective without further court action but remains subject to the court's authority to reduce or dismiss the guardian. Upon assuming guardianship duties, the guardian must notify the court responsible for probating the will. This guardianship automatically terminates when the minor attains 18 years of age.

Second, a parent who has been appointed guardian of his/her minor or adult child who is developmentally disabled may, by will, appoint a guardian for that child. However, if there has been a standby guardian designated, a testamentary guardian may not be appointed. The testamentary appointment becomes effective upon the death of the parent/guardian without further court action. The testamentary guardian assumes the same duties and powers as the original guardian had and is subject to the power of the court which appointed the initial guardian. If the court finds the will to be invalid, the appointment of the testamentary guradian is nullified. Upon assuming guardianship duties, the guardian must notify the court which appointed the initial guardian and the court responsible for probating the will.

Limited Guardian

A 1981 provision in the Revised Probate Code allows for the appointment of a limited guardian for an unmarried minor upon the petition of the parent or parents if both of the following occur:

1. the parents (or sole parent) with custody of a minor consent to the appointment of a limited guardian; and
2. the parents (or sole parent) voluntarily consent to the suspension of their parental rights.

The suspension of parental rights does not prevent the parent(s) from filing a petition to terminate the guardianship at any time. The limited guardian would have all of the powers and duties of the

parent except that a limited guardian may not consent to the adoption of the minor or release of the minor for adoption nor may a limited guardian consent to the marriage of a minor ward. The limited guardianship terminates upon petition by the parents or parents having custody or when the minor attains the age of 18."

"Plenary Guardianship

Historically, all guardians were appointed as plenary guardians of the estate, of the person or both. A plenary guardian means a total guardian. The appointment of a plenary guardian may be made only if it is clearly established to the satisfaction of the probate judge that the individual is totally without capacity to care for him/herself (plenary guardian of the person), his/her property (plenary guardian of the estate), or both."

"Partial Guardianship

The concept of plenary guardianship is very restrictive and is inappropriate for most people with developmental disabilities. Because a less restrictive type of guardianship was deemed more appropriate, the concept of partial guardianship was devised. Partial guardianship is a relatively new concept and one of vital importance to people who are developmentally disabled.

The concept of partial guardianship is based on the premise that each adult has legal rights which are separate and distinguishable. Further, none of these rights should be denied without a specific determination that an individual is incapable, due to some handicap, of exercising that right. Michigan law states that once a court determines that a person can care for some but not all aspects of his/her person or property, partial guardianship

must be used and is the preferred form of guardianship. When a probate court appoints a partial guardian of the person, of the estate, or both, the court must determine the specific rights the person cannot exercise because of his/her handicap.

The court must look at the unique situation of the individual and may not place any more restrictions or limitations on that person than those actually needed. The partial guardian may act only in those areas in which the court has specified. The ward retains the power to act in all areas not specifically limited by the court.

Having a partial guardian appointed does not indicate the ward is legally incompetent except in those areas specified by the court. Partial guardianship preserves for the individual as much freedom of choice, responsibility and independent decision-making authority as the person may be able to manage for him/herself." (Guardianship information was taken from: Guardianship for Citizens with Developmental Disabilities, A Training Package for Guardians, a publication of Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc., Elizabeth W. Bauer, Executive Director; written by: Nancy A. Sullivan, Director of Training; legal consultant: Nicholas E. Orlyk, Esq., Staff Attorney; 1984 revisions-updates: Mary L. Hines, Director of Training and Mary J. Swift, Esq., Staff Attorney (1984 Edition)

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LEGAL BASIS FOR SPECIAL EDUCATION

Constitutional Law

The United States has a long history of providing children with a public education. Handicapped children, however, have often been excluded from the classroom and denied educational opportunities. Although the United States Constituion does not specifically give children a federal right to an education, it does say that states cannot unreasonably discriminate against any one group of students.

Every state has compulsory education laws. Providing non-handicapped students with a public education while denying the same educational opportunities to handicapped students is discrimnatory and denies handicapped students equal protection of law. Denial of a state-supported right without notice, an opportunity for a fair hearing, and an opportunity to appeal the hearing decision is a denial of due process of law. Both equal protection and due process are guaranteed to every person, residing in any state, by the Fourteenth Amendment of the United States Constitution.

Because parents could not turn to a specific constitutional right to secure education for their handicapped children, they turned to the basic provisions of the Fourteenth Amendment. Parent/advocate-initiated lawsuits, filed to establish the right of handicapped students to a public education, were important in obtaining legal rights to special education and have become part of the national trend toward including handicapped inidivduals in the mainstream of society.

Statutory Law - Public Law 94-142

In response to these and other federal court cases, Congress enacted Public Law 94-142, "The Education For All Handicapped Children Act

of 1975." P.L. 94-142 was amended several times since then, the most recent amendatory act being P.L. 98-199. The act is now called "The Education For All Handicapped Act" but many people still refer to it by the old name. Either usage is permissible, but the amended title is legally preferable. Likewise, referring to the act as "P.L. 94-142" is common practice among lay advocates. Lawyers, however, will use the amended title and the full legal citation instead of the public law number.

Congress designed this act to:

> *"insure that all handicapped children have available to them a free appropriate public education which includes special education and related services to meet their unique needs."*

Congress also desired to:

> *"insure that the rights of handicapped children and their parents are protected."*

Public Law 94-142 directs each state to provide the necessary programs and services to insure that handicapped persons receive an appropriate education. It also prescribes a variety of procedures students and their parents can use to safeguard their rights. In return, the state receives federal funds for special education.

The Department of Health and Human Services (formerly the Department of Health, Education, and Welfare) promulgated regulations to implement this statute. The regulations further define the state's responsibility to each handicapped person. The federal Department of Education currently administers the regulations and funds flowing to the states through P.L. 94-142.

Section 504

Section 504 of the Federal Rehabilitation Act of 1973, P.L. 93-112, is a nondiscrimination act that provides equal opportunity to all handicapped

individuals. Section 504 states that any program or activity receiving federal financial assistance, directly or indirectly, shall not discriminate against an otherwise qualified handicapped individual based solely on the person's handicap. Most educational institutions in the country that provide special education programs and services to handicapped students receive federal dollars pursuant to P.L. 94-142. Thus, Section 504's nondiscrimination mandate applies to these institutions. The popular title for the act is "Section 504 of the Federal Rehabilitation Act of 1973." The Department of Health and Human Services has promulgated regulations to implement Section 504 and include regulations specifically governing educational programs and activities.

Mandatory Special Education Act

Michigan's Mandatory Special Education Act, Public Act 198, passed in 1971, was a forerunner to Public Law 94-142. 1971 PA 198, as amended by 1976 PA 451, is now properly referred to as "PA 451" or the "Mandatory Special Education Act." However, many people still refer to the act as "PA 198." This manual will use the amended title, "PA 451" to refer to the act. PA 451 states that schools must provide an education designed to develop the maximum potential of every handicapped individual. The State Board of Education was directed to write rules implementing the act. These rules are found in the Michigan Administrative Code.

Referral and Eligibility

Any parent, teacher, or other person can refer a student as possibly being in need of special education. WITHIN 10 DAYS AFTER RECEIPT OF REFERRAL, the school must notify the parent of the referral and request written consent to initially evaluate the student. This evaluation will be used to help the Individualized Educational Planning Committee (IEPC)

determine the student's eligibility. A student is eligible for special education if he/she:

(1) is between the ages of 0-26;
(2) has one or more of the handicaps listed below;
(3) needs special education and related services; and
(4) has not completed a normal course of study and has not graduated.

Handicapped students who may be eligible for special education services include those who are:

(1) severely mentally impaired;
(2) trainably mentally impaired;
(3) educably mentally impaired;
(4) emotionally impaired;
(5) hearing impaired;
(6) visually impaired;
(7) physically and otherwise health impaired;
(8) speech and language impaired;
(9) preprimary impaired;
(10) learning disabled;
(11) severely multiply impaired; or
(12) autistic impaired.

Determinations of specific impairments must be based on a comprehensive evaluation by a multidisciplinary evaluation team. The rules specify certain professional evaluators who must be included on the team for the different impairments. A student suspected of being severely mentally impaired, for example, must be evaluated by a team that includes a psychologist. A student who is suspected of being hearing impaired must be evaluated by a team that includes an otolaryngologist (a physician who specializes in treatment of the ear and larynx) and an audiologist.

Individualized Educational Planning Committee

In the past, Michigan used two procedures to establish a student's special education program. First, the student's eligibility/placement was determined, and then, usually at a later date and in a separate meeting, the student's individualized educational plan was written. Under the changes to the Michigan Special Education Rules which took effect in August of 1980, these procedures have been combined to form an *Individualized Educational Planning Committee* (IEPC).

IEPC Basics

Because the IEPC determines the student's individualized education program (IEP), the committee must first have information about the student. Therefore, when a student is initially referred as possibly eligible for special education services, the school must notify the parent within 10 calendar days of receipt of the referral and obtain written consent to evaluate the student. Notice of the referral must be in writing and must contain:

(1) the reasons an evaluation is needed and the type of evaluation that will be done;

(2) a description of the type of special education programs and services available in the intermediate school district;

(3) a list of organizations available to help parents understand the special education process;

(4) a statement of the parent's right to inspect all educational records pertinent to the student;

(5) a statement of the parent's right to bring any person the parent desires to an IEPC;

(6) a statement of the parent's right to obtain an independent educational evaluation;

(7) a statement of the opportunity for the parent to present information to the multidisciplinary team and at the IEPC; and

(8) a full explanation of all available procedural safeguards.

IEPC Members

The initial IEPC is scheduled by the district of residence, i.e. the student's local school district. (Subsequent IEPCs are scheduled by the superintendent of the operating school district.) The meeting must be held at a time and place mutually agreed on by the parents and school.

The superintendent scheduling the IEPC is responsible for appointing the IEPC members and the student's parents must be invited to attend.

Before the IEPC, the parents must be contacted by the school, and the school must explain the purpose of the meeting and the roles of each person who will be participating in the IEPC.

At a minimum, the IEPC membership must include a representative of the school who has the authority to provide special education programs, the student's teacher or a teacher appropriate to the student's age and ability if the student has not been previously enrolled. In addition to the parent, other persons may be invited to attend, including the handicapped student, where appropriate.

In addition, a member of the multidisciplinary team must participate in the initial IEPC and subsequently every three years when the new comprehensive evaluation is presented. This person is required to present the written report prepared by the team. The report must include, at a minimum, information needed to determine eligibility and educational data which identifies the person's current level of educational performance. A member of the team may participate at other IEPCs at the request of the parent or school.

Other persons may be invited to attend at the discretion of the parent or school, including the handicapped student or an advocate. Finally, the superintendent must give consideration to appointing professional ancillary and related personnel.

What happens during an IEPC?

Because each student has individual needs, what happens during an IEPC meeting may vary widely from one student to another. The following is a description of how an IEPC meeting agenda might look.

(1) An introduction should be made of all people present.

(2) The chairperson should state the reasons for the meeting and ground rules for conducting the meeting.

(3) A summary should be given of the reasons for the initial referral of the student, and of the kinds of assessments which were used to determine eligibility.

(4) The committee should discuss all information which might be pertinent to the determination of eligibility.

(5) If there is dissension among committee members, the committee may decide to recess so that further information can be obtained. The cost of additional testing recommended by the IEPC must be provided or paid for by the school.

(6) The committee will determine eligibility.

(7) If the IEPC finds the student eligible, the members must write an IEP or reconvene for that purpose.

(8) As information is shared, recommendations should be restated and agreements and disagreements discussed. Ask to have the recommendations read aloud so that you can agree or disagree with the wording.

(9) After consensus is reached on recommendations, someone should be assigned the responsibility for implementing each decision and a date should be set for initiating each decision.

(10) The IEPC may, after considering the least restrictive environment, RECOMMEND where the programs and services may most appropriately be provided and may inform the superintendent of the assignment options that were considered and why the recommended option was chosen. However, the superintendent, not the committee, actually decides where the programs and services in the IEP are to be delivered. The IEP shall not determine how the programs and services are to be delivered, except where this is an integral part of the placement or service itself.

(11) The committee must prepare a report for submission to the superintendent immediately after completing the IEP. The report must be restricted to programs and services actually available, but should include all programs and services necessary to provide an appropriate education to the student. Any IEPC participant who disagrees with the committee's decisions may indicate their reasons on the report or may submit a separate written statement that must be attached to the report.

(12) The chairperson should then send the report to the superintendent of the school district that is operating the program. (If this is a different district than the student's district of residence, a copy should also go to the superintendent of the district of residence).

Parent Participation in the IEPC

Parent participation in the IEPC is essential. Schools must take specific and detailed steps to insure parent participation.

(1) Each school must take steps to insure the one or both of the parents of the handicapped student are present at each meeting or are afforded the opportunity to participate, including:

   (a) notifying the parents of the meeting early enough to insure that they will have an opportunity to attend; and

   (b) scheduling the meeting at a MUTUALLY agreed on time and place.

(2) Notice of the meeting must indicate the purpose, time, and location of the meeting, and who will be in attendance.

(3) If neither parent can attend, the school must use other methods to insure parent participation, including individual or conference telephone calls.

(4) A meeting may be conducted without a parent in attandance if the school is unable to convince the parents that they should attend. In this case the school must have a record of its attempts to arrange a mutually agreed on time and place.

(5) The school must take whatever action is necessary to insure that the parent understands the proceedings at the meeting, including arranging for an interpreter for parents who are deaf or whose native language is other than English.

(6) The school must GIVE the parent a copy of the IEP.

In Michigan, the superintendent must appoint a staff person to be responsible for implementing the student's IEP. This staff person must be either the building principal or other person who will be working with the student and who is accessible to the staff.

Preparing for the IEPC

There are a number of steps that can help increase the effectiveness of the advocate within the educational system. If these are followed, it is more likely that a favorable IEPC recommendation will be obtained.

(1) ***Think about the type of educational plan you feel would be most beneficial to the student.*** Be sure to discuss educational goals with the student if possible. For instance, a student would be

more inclined to do well in a vocational program if the program addresses a subject of interest, i.e. auto repair as opposed to laundry work.

(2) *Observe the student in the present program.* This allows the advocate to develop a better perspective on how the student actually functions in the school situation. If possible, also observe the student in any other program options.

(3) *Consider the student's past programming.* What programs have been successful? Why? What programs have been inappropriate? Why?

(4) *Meet with teachers and support personnel on an informal basis* to discover what they think about the student's needs and the types of programs which would be appropriate for him/her. (Do not limit your options to programs which are currently available.)

(5) *Review all of the student's records* which are pertinent to the student's abilities and needs.

(6) *Find out who will be on the committee,* who is chairing the committee, how the decision will be made, where the meeting will be and what tools will be used in evaluating the student.

(7) *Decide whom you wish to have present.* You may wish to have someone present for moral support, to make certain you understand all that is happening, or to present additional information, such as another parent, a life consultation worker, an advocate or an independent evaluator. Be sure to contact those persons to discuss their roles and the time and location of the meeting. You should also let the school know whom you are asking to attend.

(8) *Encourage discussion and active participation by all members of the committee.* Let the committee know that you, as a parent/advocate, are present to help bring out ALL important information about the student so that the committee can plan the best program for the student. Ask questions of committee members and encourage them to speak freely, then listen attentively.

(Taken from: Special Education: An Advocate's Manual, Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, 313 S. Washington Square, Lower Level, Lansing, Michigan 48933, 1984.)

FINANCIAL AND EDUCATIONAL CONCERNS
REFERENCES

Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc., 313 S. Washington, Lower Level, Lansing, MI 48933

Special Education: An Advocate's Manual, Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, 313 South Washington, Lower Level, Lansing, Michigan 48933, 1984.

Supplemental Security Income: An Advocate's Manual, Association for Retarded Citizens/Michigan, 313 S. Washington Square, Third Floor, Lansing, MI 48933 (517) 487-5426, Revised Third Edition, June, 1984.

ADVOCACY

Edited By Marcia Nunn

Curriculum Development Specialist

A Practical Guide to Advocacy

Written by Mary L. Hines
Director of Training
Michigan Protection and Advocacy Service
for Developmentally Disabled Citizens, Inc.

MICHIGAN PROTECTION AND ADVOCACY SERVICE FOR DEVELOPMENTALLY DISABLED CITIZENS, INC.

Mandate

The Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc., is a private, nonprofit corporation established in the State of Michigan and designated by the Governor to provide protection and advocacy services to citizens with developmental disabilities pursuant to the Developmentally Disabled Assistance and Bill of Rights Act, 42 USC §6012, and the Michigan Mental Health Code, MCLA 330.1927.

Who Served

Individuals with developmental disabilities are eligible for protection and advocacy services. The term developmental disability is used to describe conditions which have in common one or more of the neurological impairments associated with mental retardation, cerebral palsy, epilepsy or autism, More broadly defined, the term refers to all conditions that develop before age 22, result in severe and chronic mental and/or physical impairment and which impose on an individual several major functional limitations which are expected to last indefinitely. There are in Michigan approximately 400,000 persons who are developmentally disabled,* about 2,600 of whom reside in State Centers for the Developmentally Disabled.**

Training Component

A primary goal of Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc. (P&A), is to promote positive change by providing informational presentations, workshops and other

training opportunities or materials. Below is a list of topics for which we can provide training to your group. To arrange a presentation, call our Lansing office at 1-800-292-5923 and ask for the Director of Training or contact your local P&A office directly. Presentations on additional topics can be developed depending on level of interest and relevancy to the enhancement of opportunities for developmentally disabled individuals.

1. ADVOCACY: includes definition of advocacy, types of advocacy, the advocate's assumptions and attitudes, assertive behavior and steps in problem-solving.

2. ATTITUDES: Information on myths and stereotypes regarding individuals with disabilities. How language conventions and media perpetuate inaccurate images. How attitudes affect behaviors toward handicappers. How to begin attitude change.

3. DEVELOPMENTAL DISABILITIES: Definition of developmental disability in state and federal law and explanation of special features of developmental disabilities. Definition and description of major types of developmental disabilities. Discussion of the philosophy of normalization.

4. DEVELOPMENTALLY DISABLED OFFENDER: Discussion of the nature of developmental disabilities and reasons for over representation of developmentally disabled individuals among inmate populations. How to identify and communicate with a developmentally disabled individual. Assistance in identifying community resources.

5. EDUCATION: Overview of federal and state special education laws. The significance of the Individual Educational Planning Committee (IEPC) and the Individual Education Plan (IEP). Parent participation in the IEPC. Rights and responsibilities within the process, educational records, problem solving, appeals and complaints.

6. EDUCATION--PARENT ADVISORY COMMITTEE: The role and responsibilities of the parent advisory committee to the intermediate school district on special education, the intermediate school district plan, plan objections and committee effectiveness.

7. GUARDIANSHIP: The nature of the guardianship relationship, alternatives to guardianship, parameters of guardianship relationships, the appointment process, rights and responsibilities.

8. MICHIGAN PROTECTION AND ADVOCACY SERVICE FOR DEVELOPMENTALLY DISABLED CITIZENS, INC.: Description of agency philosophy and background, objectives, services and structure, relationships with other groups and agencies and how to refer individuals.

9. NORMALIZATION: Background on approach to the treatment of developmentally disabled individuals. The philosophy of normalization. The implications of normalization for programs and for individuals.

10. MONITORING RESIDENTIAL SETTINGS: The significance of monitoring, pitfalls in monitoring and format for monitoring.

11. RIGHTS OF INDIVIDUALS WHO ARE DISABLED: Discussion of federal and state laws which guarantee protection against abuse, neglect or discrimination and discussion of due process dimensions of federal and state laws mandating provision of habilitative, educational or rehabilitative services.

12. SOCIAL SECURITY: Benefit programs, eligibility and applications, the disability determination process, documenting disability, rights and appeals and representing individuals in the appeal process.

Specialized Services

The kinds of problems faced by citizens with developmental disabilities and which receive the attention and specialized intervention of the Michigan P&A Service include, in part: Educational placement conflict/Lack of appropriate training programs/Exclusionary zoning practices/Denial of essential health services/Illegitimate rejection from intended financial assistance benefits/Potential pitfalls in guardianship proceedings/Exploitation and abuse/Employment discrimination/Inappropriate institutionalization/Transportation and building access barriers/Potential pitfalls in the criminal justice system.

Branch Offices

Michigan P&A Service is based in Lansing with 14 branch offices located throughout the state. The Branch Office Directors provide education and training to individuals and groups in their various

cathment areas. They also provide intervention services in resolving problems faced by citizens with developmental disabilities. Regular office hours are maintained and 24-hour answering service is available (toll-free in Michigan, voice or TTY).

Legal Component

The Michigan P&A Service staff includes a small unit of attorneys who act as a resource in support of protection and advocacy activities throughout Michigan.

The legal staff may take a case for direct representation in lawsuit after other administrative remedies have been pursued and litigation remains uniquely able to restore the rights of a large class of citizens who have developmental disabilities.

Whom to Contact

Request to help a citizen who is developmentally disabled and in difficulty may be registered by an organization or individual, community advocacy programs, people with developmental disabilities, parents, friends, local consumer organizations and public and private service agencies.

FOR INFORMATION AND ASSISTANCE, WRITE OR CALL TOLL-FREE:

Michigan Protection and Advocacy Service for
Developmentally Disabled Citizens, Inc.
313 South Washington Square, Lower Level
Lansing, Michigan 48933
(1-800-292-5923)
Voice or TTY

A PRACTICAL GUIDE TO ADVOCACY

by Mary L. Hines
Director of Training
Michigan Protection and Advocacy Service
for Developmentally Disabled Citizens, Inc.

As a parent of a child with a disability, there may be many situations in which you will want to advocate to obtain needed services or to protect the rights of your son or daughter. There may also be times when you need to be a self advocate to protect your own rights. However, many people are needlessly intimidated by the word advocacy. Advocacy is simply a type of problem-solving used in order to protect rights and/or improve the situation of another. The purpose of this chapter is to give you some basic guidelines for advocating. There are five important steps in advocacy: problem analysis, information gathering, action planning, assertiveness and follow-up. Each of these steps is discussed below.

Problem Analysis

Time spent analyzing the problem at the beginning will save you a lot of time in the long run. A good problem analysis can minimize confusion, frustration and anxiety and eliminate unnecessary steps. It may be hard to analyze a problem because you are too involved in it; but for best results this step cannot be skipped.

The questions listed below can be used as a guide for analyzing a problem. It is best to write out your answers since these notes can be used later for information gathering or during a meeting in order to keep the discussion focused on your issues. Being "too close" to a problem sometimes makes it difficult to see all sides of the situation. It is often helpful to discuss the problem with a friend or family member perhaps using the questions below as a guide.

Problem Analysis Questions

1. What is the problem? Be brief in describing the problem. If your answer is long, you have not gotten to the heart of the problem. If there seems to be several problems, rank them in order of importance, concentrating on the most important one first.
2. Who is affected by the problem? Make sure to list all persons affected by the problem.
3. How is each person you listed in your answer to question 2 affected by the problem. Be specific. List concrete ways in which the problem affects each person.
4. When did the problem start? Has it been a continuous problem? Is it worse at certain times?
5. What started the problem, made it worse or caused you to notice the problem?
6. What kinds of changes would solve the problem? Try to think of several solutions.
7. How will you know when the problem is solved?

8. What has been done to address the problem so far? What happened as a result of this? Should this be continued or does something else need to be tried? What?

9. By what date should the problem begin to be resolved? How long should this process take?

10. If the problem is not solved, how will that affect each of the persons involved?

Information Gathering

Once you have worked your way through the questions in the section above, you should have a good clear understanding of the problem and, most importantly, of the kind of changes that are needed to solve the problem. The next step is to find out which agency has authority or the responsibility for making the kinds of changes that are needed. For example, education and related services are the responsibility of the local school district; the social security administration administers the Supplemental Security Income (SSI) benefit program, community mental health provides respite care, and your local transportation authority provides accessible transportation. In some situations responsibility is a little more difficult to determine. If there are no curb cuts or no accessible housing in your city, the governing body of the city is responsible. If you do not know what agency is responsible, do not give up - ask. Agencies to call for further information are listed on the last page of this chapter.

Once you have identified the responsible agency, you need to know who within that agency can make the changes you need. For example, some changes in your child's educational services, like changes in teaching methods or materials can be made by a teacher. Other changes in the educational area like adding physical therapy to your child's school program need to be made by the Individualized Educational Planning Committee (IEPC).

In addition to knowing who can make changes, you need to do some research to find out more about the agency's responsibility to make the changes you desire. In other words, is there a law, rule, regulation or policy that describes what the agency must do. When you look into what the law says, you will find one of three situations. One, the law may require an agency to make the kind of change you need and, therefore, you have a strong case. In a second type of situation, the law may say that the agency can make the kind of change you want, but the law does not say the agency must make this change. This is the most common situation. The law often describes the kinds of services an agency may provide to its clients or students. The services that an individual actually receives depend on the person's needs as supported by reports and other documentation and by what is specified in an individualized service plan. What this means for you is that the kind of changes you will be advocating for are negotiable. Whether or not they are made will depend on preparation, persuasion, and power. Finally, the law may not even address the situation you are interested in. In

this case you may want to advocate for the changes because they are appropriate to your problem. You may also want to find other persons with similar problems and talk about working as a group to bring about change.

Once you know whether any laws, regulations or rules apply to your situation, you need to plan your argument. This involves identifying all of the reasons why the change must or should be made and deciding which you will use. Reasons could include violations of laws, regulations, rules and policy, and description of the consequences of the problem on rights, health, welfare and so on. You have already done part of your research if you answered all of the questions in the problem analysis section. Questions 3 and 10 of that section asked you to identify the consequences of the present situation. You need to translate that information into an argument about why the change is needed. It is also helpful to try and come up with reasons why the agency could benefit from making the change.

Action Planning

Advocacy involves action. Now that you have analyzed the problem and collected information about solutions it is time to plan what action you will take. There are a number of rules of thumb for planning.

1. Know what you want to accomplish.
2. Start by talking informally to the person most directly associated with the problem. Move to higher levels only if the problem cannot be solved by speaking to the caseworker, teacher or other direct service provider.
3. Although a previous section described the importance of researching and understanding how law and formal policy applies to your situation, do not start your discussion by talking about law and never try to sound like a lawyer, unless you are one.
4. Start by describing the problem as a concern and by emphasizing the kinds of consequences the problem has for you and your son or daughter. Ask for ideas on what could be changed to solve the problem. Show that you are interested in solving the problem and in working with the provider to do this. Do not be harshly critical or attacking in your approach. This can create strong defensiveness and get in the way of problem-solving.
5. Observe the type of response you get and assess how willing the person is to really change things. If ideas are offered, make sure they are specific and concrete and that a timeframe is included. Do not be content with vague statements like, "we will look into it." Ask when the person will let you know.
6. Never feel guilty about speaking up for your child's needs or for your own needs.

7. Always keep a record of who you talked to, their position, the date of the conversation or meeting, a summary of the issues and any agreements reached, including who is to be responsible for doing what and the dates for the completion of activities.

8. If you have not solved the problem, go to a more formal step. Arrange a meeting with a supervisor or other responsible administrator to discuss your concern. Confirm this meeting with a letter which outlines why you would like to meet. This letter should be brief; you should not go into great detail in this letter. Save the details for the meeting.

9. Prepare for the meeting carefully. To do this, go back to the information you collected when analyzing and researching the problem. Outline a statement of the problem, reasons why you feel it must be resolved and options you feel would resolve the problem. Make copies of relevant laws or policies. Review notes from your discussion with the direct provider especially noting reasons why she or he felt the problems could not be resolved. These reasons are likely to crop up again. Think of arguments in response and if possible consult with an advocate about points to include or emphasize. Organize your notes and papers carefully, so when you need to refer to them, they will be handy.

10. Make sure you know how to find the place where the meeting will be held and that you arrive on time. Dress in a conservative, professional style. The meeting will probably be held in an office or conference room. This is someone else's territory and will probably contain items that make you aware of the power and credibility of the administrator, such as a large desk or conference table, diploma or advanced degrees, name plates with long titles and so on. This type of environment sometimes makes people feel nervous. Remember that symbols of power have an effect only if you allow them to. Keep youself focused on your purpose.

11. Keep the meeting on a business-like basis. If anything is said that you do not understand, do not feel foolish about asking for clarification. Every profession and field of work has its own jargon and you should not be expected to understand jargon. Take notes and take your time.

12. When it comes to a resolution, make sure that you understand what will be done and when. Send a letter of thanks for the meeting. Summarize the agreement in this letter to confirm it.

13. If the problem is not resolved, request a formal appeal. Agencies should have a pamphlet describing procedures for appeals. Ask for this pamphlet and contact an advocate for assistance.

Assertiveness

In previous sections we discussed analysis, research and planning. The points you plan to make, must be made assertively to be maximally effective. As a parent of a special needs child assertiveness is an important skill and it is a skill that anyone can learn. There are many assertiveness books available in libraries and bookstores, and courses available through schools and clubs. If you are not assertive, you will find the effort to become more assertive is worthwhile for your child and for yourself. Below are a few assertiveness hints.

1. Your tone of voice is as important as what you say. Do not talk too softly or too loudly: use a normal conversational volume. Be careful about how you end your sentences. A slight rise in voice pitch at the end of a statement makes you sound like you are asking a question or are unsure. Speak clearly and use words that are natural and familiar to you. Do not use jargon or more formal words than usual. Be simple, direct and clear. Ask a relative or friend to practice talking about the problem with you if you feel you need feedback and practice on your voice.
2. Maintain eye contact when speaking. Looking down or away makes you look unsure.
3. Maintain a straight but relaxed looking posture. Practice with a full length mirror to find what looks and feels right for you. Your posture should communicate energy and confidence. Crossed arms and legs usually indicate defensiveness.

4. Try to keep your hands still. Fidgeting communicates nervousness. If you must do something with your hands, take notes.

5. Smile and shake hands when greeting the people you are meeting with. A firm, solid handshake communicates confidence. Do not maintain a frozen smile throughout the meeting however; a neutral facial expression is better.

Follow-up

Your advocacy is not over when the meeting is finished. Follow-up is just as important as preparation. Send a letter confirming agreements reached. Keep a copy of this letter, your notes, all correspondence received from other people involved with your advocacy activities and any other relevant material. No one's memory is infallible and if others do not follow through you may have to refer to your records. Finally, monitor to make sure each party follows through with agreed upon changes or activities.

Conclusion

Advocacy takes work but the satisfaction of knowing your child's welfare is enhanced through your efforts, make it rewarding work. Your advocacy efforts will be less stressful and more successful if you seek support and advice from other parents and professional advocates. Some helpful contacts are listed on the next page.

PROBLEM/NEED	AGENCY	ADDRESS	PHONE NUMBER
Mental retardation information, rights, support, legislation and advocacy.	Association for Retarded Citizens/Michigan	313 S. Washington Sq. Third Floor Lansing, MI 48933	(517) 487-5426
Information on handicapping conditions, rights, services and advocacy.	Center of Independent Living (nine locations in Michigan)	Call Michigan Council of Independent Living Centers Directors for referral.	(313) 971-0277
Information on deafness, services, rights, referral for advocacy assistance.	Division for Deaf and Deafened	Department of Labor 309 N. Washington Sq. P.O. Box 30015 Lansing, MI 48909	(517) 373-0379 Voice/TDD
Developmental disabilities information, assistance and support.	Easter Seal Society of Michigan, Inc.	4065 Saladin Dr., S.E. Grand Rapids, MI 49506	(616) 942-2081 1-800-292-2729
Epilepsy information, services and referral to support groups.	Epilepsy Center of Michigan	3800 Woodward Avenue 7th Floor Detroit, MI 48201	(313) 832-0500
Learning disability information and advocacy.	Michigan Assoc. for Children and Adults with Learning Disabilities	20777 Randall Farmington, MI 48024	(313) 471-0790
Emotional illness information and education problems.	Michigan Assoc. for Emotionally Disturbed Children	23555 Northwestern Hwy. Southfield, MI 48075	(313) 356-2566

PROBLEM/NEED	AGENCY	ADDRESS	PHONE NUMBER
Information on handicapping conditions, services, rights and some advocacy.	Michigan Commission on Handicapper Concerns	Department of Labor 309 N. Washington Sq. P.O. Box 30015 Lansing, MI 48933	(517) 373-8397 Voice/TDD
Advocacy denial of services, general information on developmental disabilities, training and audio-visuals.	Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc.	313 S. Washington Sq. Lower Level Lansing, MI 48933	(517) 487-1755 1-800-292-5923
Autism information, support, rights and advocacy.	Michigan Society for Autistic Citizens	2002 Hogback, Suite 18 Ann Arbor, MI 48104	(313) 973-9004
Blindness information.	National Federation of the Blind - Michigan	3761 Roosevelt Dearborn, MI 48124	(313) 563-3900
Denial of rights in Department of Mental Health Services.	Office of Recipient Rights - Department of Mental Health	Call facility for referral to the ORR offices.	
Spina bifida information and support.	Spina Bifida Assoc. of Michigan	P.O. Box 93 Shelbyville, MI 49344	(517) 332-5754

ADVOCACY REFERENCES

Hines, Mary L., Director of Training, Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc.

Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc., 313 S. Washington Square, Lower Level, Lansing, Michigan 48933.

SOCIAL SKILLS

Edited By Marcia Nunn

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Social Competence

A great deal of energy has been expended in the recent past by parents and professionals in the field of developmental disabilities to offer children and adults with disabilities more opportunities for social experiences and a wider exposure to activities in their own communities. To integrate disabled persons in the every day events and activities that we all enjoy. This thrust toward "normalization" has required persons with disabilities to improve and refine skills that are considered to be appropriate in a variety of situations.

These skills are the same for persons with disabilities as they are for all of us: being able to get along with others (family, peers, friends, etc.), communicating effectively with others, and learning to cope with the frustrations of social living.

Existence in our society is a very complex one and requires a great deal of developmental learning and skill mastery to function appropriately in a community. A person must acquire distinctive behaviors for home, school, work, and to deal effectively with friends and others. Because persons have a developmental disability are sometimes protected and may be withheld from various situations, it is necessary to devote time and attention to the development of coping skills, to the establishment of an identity, and to the learning of appropriate behaviors in a variety of situations.

Following are some characteristics that are fundamental to social acceptance.

Physical Appearance

Interactions with a persons environment helps him to form self-confidence and aids in the formation of his identity. How other

people react and respond to him influences how he feels about himself (good, bad, ashamed, etc.). The degree to which a disability is visable to others will determine, in part, his chances for social interactions and acceptance.

* For a person to be regarded as physically attractive, it is important to choose an appropriate hairstyle and attractive clothing.

* If a person has difficulty with dressing due to motor control, his clothing can be adapted for ease in closure (velcro or snaps can replace buttons).

* For individuals with back or leg braces, clothing can be designed with extra room for a more comfortable fit.

* Sometimes to enhance the physical appearance of a persons face, consideration can be given to make-up, wigs and hairstyles, eyeglass frames, sunglasses, clothing with necklines complimentary to the face, verbal instructions on how to hold the head and appropriate facial expressions.

Social Coping Behavior

The development of good coping skills is dependent on interactions with others. These social interactions need to be with many different people (disabled and non-disabled), they need to happen often and they need to happen in a variety of times, places and situations. Persons with developmental disabilities need to be in the "real" world in order to learn, establish, and maintain satisfying interpersonal experiences.

Acceptance

Everyone needs to accept themselves and to be accepted by others in order to feel a part of society and a part of his own community. When persons with developmental disabilities are confined to interactions with other persons with disabilities, they will form standards of behavior limited to that reference group. A good frame of reference for evaluation of self and others would include your family group, your

ethnic group, your peer group (disabled and non-disabled), your church groups, etc. Your social awareness and competence would evolve from interactions with all of your acquired reference groups.

Self-Fulfillment and Assertiveness

The emotional needs of persons with disabilities are the same as they are for all of us:

"1. The need to be loved and accepted unconditionally.

2. The need for security--to be safe and relatively free of threat.

3. The need to belong, to be a part of the group, and to feel identification and acceptance.

4. The need to be recognized, to gain approval, to feel significant and accepted.

5. The need to be independent, to take responsibility, and to make choices." (Education of the Trainable Mentally Retarded)

The needs are characteristic of "normalized" experiences. If the above needs are met, a person can experience and recognize their feelings and in turn learn to accept themselves as competent individuals. Self-fulfillment is established through the process of individualization, becoming a separate and distinct individual. If a person with a developmental disability is allowed to achieve independent behavior, he has the potential for expressing his right to his own identity and for expressing assertive behavior that involves choices in accordance with his own needs, while at the same time encouraging others to do the same. He expresses what he feels, what he thinks and then makes choices, without infringing on others rights to do the same.

Dating, Marriage, and Sexuality

"When he was young, he played house like other children, was "Daddy" surrounded by his sister's dolls. He often said, "When I grow

up and have children..." but as he grew older, I realized he was saying it as a question, as though awaiting--or dreading--affirmation or denial." (Taken from Our Special Child, 1981)

For some persons with developmental disabilities, marriage and parenthood are not only feasible, but many disabled persons have adjusted very well to married life (as well, in fact, as non-disabled persons). For others, a relationship outside of marriage may be more appropriate. People are much more accepting today of lifestyles other than marriage. However, whether a person lives alone, in an apartment, or with a roommate, marries and has children, marries and does not have children, or lives with several people of his own age in a communal living arrangement, an intimate relationship can enrich his life and allow for sexual expressions in a socially acceptable manner.

Dating

Most adolescents develop an interest in dating, adolescents with developmental disabilities are no different than other adolescents.

"Through interactions with other teenagers in class and activities, a disabled person is very likely to want to date as other teenagers do.

Young people usually have far more experience in relating to members of their own sex, and, at first, may feel threatened and nervous with members of the opposite sex. The physically impaired, in particular, often worry that their braces, artificial limbs, wheelchairs, awkward body movements or speech may cause them to seem unattractive, and lead to rejection. Double dates and group activities are easier in the beginning and provide the opportunity to learn how

to relate better with girls or boys. Whether they are school friends, workshop or job acquaintances, neighbors or whatever, these warm-up experiences can help reduce between-the-sex tensions. Being with other people requires a certain degree of self-confidence for anyone." (Taken from: The Disabled & Their Parents: A Counseling Challenge)

Because most disabled teenagers are not emotionally prepared for the intimacy and involvement of sexual relations, it is important to spend time to help prepare them realistically and positively for their own future.

Marriage

"Contrary to several beliefs, many disabled people marry and adjust very well to their situations. Others, just like any group of people, never wish to marry. Of course, some want to marry but are afraid they cannot."

"Some young people feel sorry for themselves and decide in advance that nobody will ever love or marry them. This becomes a self-fulfilling prophecy: nobody will love us unless we let them and unless we love ourselves. In any case, personal preferences are important. Not everyone need be married. More and more people are proving that the single life is a valid one.

Some parents insist, as an absolute prerequisite, that their offspring be capable of financial independence before undertaking marriage. This is an important consideration. These parents may rightfully not wish to support the marriage for years. If at least one partner is employable, this may not be a problem. Yet, if neither can work, and if their families had planned on supporting their children anyway, sharing the expenses of providing for a couple, instead

of two individuals, can be a wise decision and even save money. Marriage gives many disabled individuals a great feeling of independence as long as some agreeable arrangements can be worked out.

The success of a marriage certainly depends on more than adequate finances. It is imperative that each person feel emotionally mature enough to deal with the other person's problems and the problems they share. This usually involves responsibility and work: cleaning, dishes, repairs, shopping, laundry, cooking, etc. When people live with each other, the sharing of these "little" things can become the focus of major disagreements. They must be helped to understand that much of married life is similar to unmarried life: unexciting routine." (Taken from: The Disabled & Their Parents: A Counseling Challenge)

Sexuality

"Sexual relationships without marriage, in the normal population, have become more and more common and more accepted. Many parents who, 10 years ago, would have been devastated by the sexual activity of an unmarried daughter or son, now accept a variety of arrangements.

This change in parental attitude does not seem to be as readily extended to mentally handicapped daughters and sons. Some parents are so concerned about the possibility that their adult children may have a sexual experience, that they never allow a friendship to blossom. Yet, having a close friend may be the best experience a handicapped person can have. A great deal of comfort and joy can be derived from holding hands, hugging, touching, having someone special to look forward to seeing, to go places with, to call on the telephone, and to talk about and think about. Although close friendships may lead to sexual intimacy, many do not."

"Parents teach their children about sexuality and social behavior whether they mean to or not. Our attitudes are revealed to our children day after day."

"The best teachers are those who feel at ease, and who can be open and honest and direct. For most parents, talking about sexuality is not easy--at least not at first. Some things you can do to become more comfortable are:

1. Become aware of your own attitudes. How did you learn about sex? How would you like to have learned about sex? How have your ideas about sex changed? Are they similar to your parents' ideas? Do you have religious beliefs that influence your attitudes about sex? Have you had some unpleasant sexual experiences? Have your experiences been mostly good? Do you expect your children to meet all of the standards you have set for yourself? Do you have friends whose lifestyles and attitudes about sex differ from yours?

2. Get some factual information by reading books and by going to classes on sex education.

3. Share your feelings with other parents--your hopes, worries, questions. Get a group of parents together. Ask a sex educator who has had experience with mentally handicapped children and adults to meet with you.

4. Practice! Pretend you are talking to your child about sex--use a mirror or a tape recorder. Try to explain menstruation or wet dreams in the simplest terms possible. Then practice with a close friend, or other parents, until you are comfortable using sexual words, including the slang words. Children can and should be taught the more polite language, and the earlier the better. But they also need to understand the street language, because it gives them some protection against ridicule by others who use it.

5. Grab the teachable moment--a picture in a magazine, a pregnant friend. If your child hugs someone it is inappropriate to hug, show your child then and there how to shake hands instead. If your child asks questions about sex, consider yourself lucky! Answer honestly, don't evade. If you don't know the answer, say you'll find out, and do so. Be ready to repeat and repeat, and to ask your child questions to make sure that your explanation is understood. Getting up the courage to talk about sex once or twice won't do the job.

6. Look for visual teaching aids that you might borrow. Some county health departments, schools, and Planned Parenthood centers have simple charts, slides, films, models, menstrual kits, and dolls that are anatomically correct.

7. Relax! If you are trying to give accurate information, even if you don't know all the answers, you're well ahead of the person who gives no information at all. Studies show that children whose parents have discussed sex with them, no matter how poorly, are far more likely to be responsible people, sexually. If you can deal with sexuality in the context of everyday life, as you do with health, safety, meals and manners, it becomes less threatening. Every child needs to be able to talk to someone about sexual concerns.

8. Keep your sense of humor. It's a good teaching aid. We have found that a little laughter in sex education classes makes it easier for everyone to talk and to ask questions. It holds the attention and helps the learning process.

9. Expose your child to friends who have a variety of life-styles which suit them. Make sure your child knows that marrying, mating, and having children is not the only acceptable pattern of life. Role models who do not fit this pattern will give them a better chance to feel good about themselves, particularly if marriage or parenthood are unlikely options for them." (Taken from: An Easy Guide for Caring Parents: Sexuality and Socialization)

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LIVING ALTERNATIVES

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LIVING ALTERNATIVES

Disabled persons grow up. It is normal for children to live with their parents and it is normal for young adults to move out of the home and start a life independent of their parents. For persons with disabilities there are a number of options that can help to enrich and expand their independent living (living on one's own, managing one's own life, making one's own decisions).

Semi-Independent Living. "For retarded residents, semi-independent living arrangements may be transitional or permanent environments. A major difference between these programs and group home programs is that semi-independent living programs provide support for residents with less supervision and with little or no structured training. Semi-independent living in an apartment offers the resident a high degree of autonomy. Usually, residents living in these programs live one or two to an apartment or duplex located in a single family residential neighborhood or one zoned for multiple family dwellings. The residents are skilled enough to manage most of their own financial affairs, are wage earners, and can make productive use of their leisure time. In some cases, semi-independent living can be achieved when a person who likes to cook but is a poor money manager decides to share an apartment with someone who can handle the financial affairs but is not very good in the kitchen." (Mental Retardation: From Categories to People)

Foster Home (up to 3). "Licensed foster family that is paid for residential and meal expenses and provides opportunity for personal relationship in a family-like atmosphere." ("Focus on the Retarded Adult, Programs and Services")

Temporary care home (usually 1 at a time). "Licensed foster home that provides short-term emergency care for retarded persons (child or adult) outside the family home during emergencies or vacations. Provides competent daily sitting arrangements for the retarded person for weeks or longer periods of time. The arrangement is not intended to be permanent. ("Focus on the Retarded Adult, Programs and Services")

Family group home (4 to 6). "Provides short-term care for emergency placement, for family vacations, or for trial separations. Retarded residents usually are of similar age and level of development and peer experiences are emphasized." ("Focus on the Retarded Adult, Programs & Services")

Group Homes. "Small group homes with 8 to 12 residents and 4 to 6 staff represent a good living and training alternative for moderately and severely retarded people in the community. For retarded people entering the community from institutions, group homes can provide the structure and training necessary for a successful transition while, at the same time, providing a more normalized homelike environment."

"While training in the home and daytime work activities provide a good deal of structure to the lives of people living in group homes, there is also considerable flexibility for individual choice in recreation and leisure activities. For the retarded person living in a group home, life is not unlike being a member of a large family. There are group activities, such as meal preparation and family meals, and there are individual responsibilities, such as maintenance of one's own room.

Training in the group homes is based on the individualized needs of the residents. Generally speaking, training may encompass the following areas:

1. Personal care, grooming, and hygiene
2. Shopping and meal preparation
3. Prosocial behavior
4. Money management and budgeting
5. Use of leisure time
6. Use of community resources such as public transportation

Training is an essential transition function of group homes." (Group Homes section taken from Mental Retardation: From Categories to People)

Halfway house (up to 15). "Designed primarily to offer a bridge between the state facility, the family, or the foster home and more independent living arrangements in the community for the retarded person who has demonstrated some degree of independence and self-determination and requires assurance and experimentation in a more structured setting. Short-term residence arranged to test readiness for independent living and the impact of separation from the family. Evaluation and training for independent living may be provided." (taken from "Focus on the Retarded Adult, Programs and Services")

AIS/MR Alternative Intermediate Services/Mental Retardation. A community-based home setting for those developmentally disabled individuals that require more extensive health care and/or remedial self-help maintenance than presently available in contract or adult foster care settings. These homes are established, funded and supervised by the Department of Mental Health through their local Developmentally Disabled Centers.

Nursing homes (varies in size). "Twenty-four-hour professional nursing care and regular medical services and medication, as needed, are provided. Eligibility depends on a debilitating illness.

State institutions (varies in size). Increasingly, state residential facilities have established short-term admission procedures for a trial separation from the family, for residence during a family crisis or vacation, to obtain specific medical treatment, or for behavior modification training." ("Focus on the Retarded Adult, Programs and Services")

Respite care and other family services. "The most independent, normal, and least restrictive residential environment for young persons is within

the natural family unit. While it is "normal" for children to move out on their own when they reach adulthood, many retarded adults continue to live with parents or other relatives, sometimes by preference, sometimes for lack of suitable alternatives. Several programs support a family's efforts to retain a retarded member in the natural family unit. One of the most important of these programs is respite care.

When a family has no relief from the daily responsibilities necessitated by the handicapped member of the family--no time for themselves, no one to turn to in emergencies--then frustration, isolation, and fatigue steadily mount. Temporary relief from care through provision of respite care services can enable family members to spend a relaxed evening away from the home, to keep medical appointments, to attend funerals, or to take a summer vacation." (Independent Living and Mentally Retarded Persons: The Role of Independent Living Programs)

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WORKING ALTERNATIVES

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Vocational and Day Programming Options

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Working at a job is a very important part of adult life for most individuals in our society. Individuals with disabilities are no different from others in their desire to work, learn and socialize. Work and related activities build self-esteem, increase relationships and usually result in an income. However, not everyone is able to work competitively. Some disabilities make regular, full-time employment impossible or unsuitable. In this case, the continuum of work and day activity options must be examined to find a program suitable for the individual. The purpose of this module is to describe the continuum of work and day activity options for individuals with disabilities. We will also discuss how best to help your son or daughter prepare for work and related options and mention resources for further information and assistance.

Competitive Employment

Many individuals with disabilities will select a full-time job in the competitive labor market based on personal ability, interests and preparation. In the past it was assumed

that individuals with disabilties could only do certain types of work. For example, individuals who are blind were trained to make brooms, cane chairs and rag rugs. Now individuals who are blind work at a wide range of jobs, including; lawyer, secretary, teacher, salesperson and so on. There are some constraints, but when viewed objectively, opportunities far outweigh constraints.

Breaking into the world of work is often harder for persons with disabilities due to employer lack of information or prejudice. There are laws which prohibit discrimination in employment based on handicap. It is important to be aware of these laws and the protections they provide. Section 504 of the Rehabilitation Act of 1973 prohibits employment discrimination by any employer who receives federal money. This includes most jobs in government, education, health service, and transportation. Section 503 of the Rehabilitation Act of 1973 applies to private employers who have federal contracts amounting to $2500 or more. The Michigan Handicappers' Civil Rights Act (PA 220) prohibits discrimination by any employer in Michigan with four or more employees. These laws require more than nondiscrimination; they require the employer to provide reasonable accommodations to an otherwise qualified handicapped employee. Reasonable accommodations include provision of adaptive aids or equipment or other changes in the job site or organization of the job tasks to eliminate barriers to performing a job due to a handicap. An otherwise qualified handicapped person is one who can perform the essential duties of the job with reasonable accommodations.

Protection from discrimination is not always enough to land a job. Job hunting is a difficult and stressful experience for most individuals and can be even more so for an individual with a disability. The state vocational rehabilitation agencies provide a wide range of services in order to help a person with a disability prepare for and find a job. The services available include, but are not limited to; evaluation of work aptitudes and interests, job counseling to help select a type of suitable work, job training and related services, job site analysis to determine if reasonable accommodations are needed, training in job search and interviewing skills, and job finding assistance. There is no charge for services from the state vocational rehabilitation agency. It is important to contact the local vocational rehabilitation office at least one year before a student is ready to graduate from high school or to leave special education. A vocational rehabilitation counselor can be a good resource in vocational planning before the student applies for services.

If the student is considering post-secondary training, the vocational rehabilitation counselor can help in planning and meeting extra training expenses related to the disability. The vocational rehabilitation agency which serves individuals who are blind is the Michigan Commission for the Blind. Michigan Rehabilitation Service is the vocational rehabilitation agency serving individuals with disabilities other than blindness. Further information and help in finding the local office serving your area is available by calling a toll free number. This number is 1-800-292-5923.

The Continuum of Work and Adult Activity Options

Individuals who are not ready to move from special education into the competitive work force or higher education need a program which can help build skills in the areas of self-care, communication, socialization, pre-vocational and vocational activity. A continuum of program types is needed because individuals differ greatly in abilities and needs. The continuum of program types includes; adult activity, work activity, sheltered employment, enclave employment, the supported employment model, and competitive employment. In many areas of the state, this full continuum of options is not available. The availability of an adequate continuum of options is important since it allows individuals to be served in a program which meets their needs and to move to a higher level of programming when they are ready. When the continuum is not adequate individuals may have to wait a long time before placement into a program, the program may not match the individuals' functional level, individuals may not be encouraged to develop skills since there is not a "next step" in programming, or individuals may not have steady, full day programming.

The lack of an adequate continuum may be due to a number of factors, such as; insufficient funding and other resources, lack of knowledge about how to develop programs that are consistent with a developmental approach or lack of commitment

to the normalization principle. It is important to find out what types of programs are available in your area before your child leaves special education. In addition you will want to know how eligibility for programs is determined and whether there are waiting lists for admission to programs. If there is not an adequate continuum of program types or if the programs are filled to capacity and unable to take new clients, you should seriously consider working with other parents and advocacy groups to improve the availability of programs in your area.

Types of Vocational and Day Activity Programs

There are at least five types of day activity and vocational programs. There are; adult activity, work activity, sheltered employment, enclave programs, and the supported work model.

Adult Activity Programs

Adult activity programs serve people whose most important needs are to learn self care skills, communication skills and socialization skills. Self care skills include toileting, dressing, eating, and personal hygiene. Socialization skill development is aimed at learning and practicing behaviors accepted by society to increase the types of situations and environments that an individual can move into. Speech therapy, physical therapy, occupational therapy,

and health and counseling services are usually available to clients in an adult activity program. An adult activity program may have several program levels, such as; entry, intermediate and advanced levels. At intermediate and advanced levels clients learn pre-vocational skills.

All programming provided is described in an individualized program plan. As program objectives are achieved new ones are developed until the client is ready to move to a new program level and eventually to a new program type (and usually a work activity program). To find out about adult activity programs in your area contact your community mental health agency.

Work Activity Programs

Work activity programs teach pre-vocational and vocational skills and social behaviors needed in a work place. Individuals may perform work tasks, such as; sorting, assembling and packaging, but the emphasis is on teaching these tasks not on amount produced. Individuals also participate in adult basic education and many programs also offer training in self advocacy and decision-making. A heavy emphasis is placed on teaching work behaviors like; arriving on time, staying with work tasks, getting along with co-workers, relating to supervisors, dressing appropriately for work, taking responsibility for work areas and tools and learning good safety practices. Speech therapy, occupational therapy, physical therapy, and mobility and transportation training may also be available. Work activity programs may be available through your local community mental health board.

In a work activity program, clients work on learning behaviors in accordance with an individualized program plan as developed by the community mental health board staff. As skills are mastered, new objectives are added to challenge the client and further develop skills. Work activity programs usually group clients according to skill level and clients may progress from entry level to advanced levels until they are ready to move to the next program type.

Sheltered Employment

In a sheltered employment program clients actually work for pay, but work or produce at a significantly slower rate than expected standards in business and industry. The types of work done by clients have traditionally been industrial tasks like assembling machine parts or packaging materials. There are standard levels of productivity for different tasks. A client's productivity is compared to this standard level and the client's peformance is reimbursed by a percentage of standard productivity. The closer the client's productivity rate is to 100%, the closer that client is to producing what is expected in a competitive job of the same type. This percentage along with information on the client's work relevant behavior are a rough way to tell when a client is ready to move to a work enclave, a supported work opportunity, or into regular, competitive employment. Like the program types discussed above, sheltered employment programs may provide related services, such as; adult education, independent living

skills training, counseling, and physical or occupational therapy. These services may be available through a community mental health agency, vocational rehabilitation agency or school district.

Enclave Employment

Enclave employment is like sheltered employment since individuals usually take longer to finish work tasks and need closer supervision than individuals in competitive jobs. A major difference between sheltered employment and work enclaves is the work site location. Work enclaves are located in regular businesses or industries. A enclave consists of a group of individuals with disabilities who do a particular job or job task at a regular job site under the supervision of a person trained to supervise individuals with disabilities that affect work performance. Work enclaves have more normalizing potential than traditional sheltered employment since individuals work in the same environment as nonhandicapped persons and have opportunities to observe, meet and interact with a greater number of nonhandicapped persons.

Supported Work Model

The supported work model is a new concept in employment of persons with developmental disabilities. It does not fit neatly into the continuum we have described. It is really a different approach. Of the options discussed above, it is most like enclave programs. In this approach, work experience

begins early while an individual is still in special education. In Wisconsin, for example, students spend one half day a week learning a job at a business or other work place in the community beginning at age eleven. The amount of time a student spends working is gradually increased each year until graduation from special education.

Staff of this type of program actively research the community to find jobs in businesses and agencies that can be done by individuals with severe disabilities. This research involves contacting employers, discussing the type of work done and spending considerable time watching and analyzing jobs and workers at businesses in the community. Disabled individuals are then carefully matched with jobs to find an opportunity that best fits an individual's interests and limitations. A job coach teaches the disabled individual how to do the job at the job site. The job coach also studies how the job site is structured and set up to find ways to adapt it to the disabled person's limitations. Once the job is learned, the job coach fades out of the picture but continues to visit and be available in case problems occur.

This type of job program has been successful in placing individuals with severe mental retardation. The supported employment model is more similar to competitive employment than the other program options. In this model, disabled persons are placed individually at different work places and job coaches go out with them individually to teach the job and ensure successful adjustment. In other program types individuals with

disabilities are grouped together either at a separate location or within an enclave. An individual with a disability is most likely to be successfully integrated when co-workers get to know him or her personally. This is more likely to happen in a supported employment model than in an enclave program.

Helping Prepare Your Child for Work or Other Meaningful Day Activities

1. Disability is only one factor that affects opportunities for work. Personal habits, motivation, cooperation and ability to accept supervision are some very important qualities that affect work opportunites for all persons. You should begin to work with your child now to develop these qualities.
2. Have some expectations for your child. Although your child may not achieve what the average child does your child will achieve his or her own special triumphs. Your encouragement to grow and develop at his or her own rate is essential. Praise successes lavishly and support and comfort the child when failure occurs. Recognize that there is always risk in growth. Protect your child from unreasonable risks but be careful about overprotection.
3. Help your child get the best education and training possible. Be an active participant in your child's Individualized Educational Planning Committee (IEPC). Make sure you understand the IEPC process and each

year's plan. Learning objectives should be specific and clear. If your child is not making progress, the plan needs to be changed since all children can learn although they may learn at very different rates.

4. Individuals are eligible for special education until they graduate with a regular high school diploma or reach the age of 26. Special education includes vocational training. If your child is not pursuing a regular academic course of study, make sure pre-vocational and vocational training is included in his or her Individualized Educational Plan (IEP). Encourage your child to stay in school long enough to get the maximum amount of training he or she is eligible for.

5. Find out what kinds of employment options are available in your community before your child needs them. Opportunities vary widely from one area of the state to another. If the continuum of services described in this module is not available in your community, become active to expand program opportunities. The Association for Retarded Citizens/Michigan has developed two excellent handbooks describing how to influence programs for developmentally disabled individuals through the community mental health board planning process. (Community Mental Health Board Planning: A Handbook for Effective Advocate Participation and A Handbook of Advocacy Techniques for Use with the Community Mental Health Board Planning Manual.)

6. At least one year before your child will leave special education invite a vocational rehabilitation counselor to participate in the IEPC to ensure proper vocational assessment and counseling are available and to provide a transition from school to work.

Financial Considerations

When an individual receives social security benefits, it is important to find out how income from work will affect benefits. Income must be reported to the Social Security Administration. When an individual who receives Supplemental Security Income (SSI) benefits earns more than $75 in a month, that month is counted as part of a trial work period. A trial work period consists of a total of nine months of earnings of $75 a month or more. These nine months need not be consecutive. During the nine trial work months, SSI benefits are continued.

After nine trial work months, ability to work is reviewed by the Social Security Administration. If the individual earns $190 a month or more in competitive employment she or he will be considered able to work and benefits will stop. If the SSI recipient is in sheltered employment, she or he may earn up to $300 a month before benefits are terminated (after nine trial work months).

After the trial work period is used up some individuals continue to receive SSI benefits because the amount of money they earn is below the amounts described in the paragraph

above. The SSI benefit amounts for these persons will be reduced in proportion to the amount earned. To estimate the amount by which benefits will be reduced, do the following:

1. Take the amount earned per month and subtract $85, since $85 can be exempted from reduction.
2. Take the results of this subtraction and divide it in half. This is the amount by which the SSI check will be reduced.

Concern over loss of social security benefits is important and sometimes prevents persons from trying to reach their maximum potential in the work place. Sometimes there are ways to minimize the risk of losing benefits like; documenting employer subsidy, a plan to achieve self-support, income exclusions for work related expenses, or ways to continue medicaid or medicare benefits although SSI cash benefits are terminated. It is essential to get information and advice about how work will affect social security benefits. You can get this kind of information from community mental health agencies, vocational rehabilitation agencies and other service providers or from advocacy agencies like Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc.

Resources

Vocational Rehabilitation

Client Assistance Program
Michigan Rehabilitation Services
Michigan Department of Education
P.O. Box 30010
Lansing, Michigan 48909
(517) 373-8193 or 1-800-292-5896

Community Mental Health Board Advocacy Manuals

Association for Retarded Citizens/Michigan
313 S. Washington Square, Third Floor
Lansing, Michigan 48933
(517) 487-5426

Information, referrral, training and advocacy

Michigan Protection and Advocacy Service for
Developmentally Disabled Citizens, Inc.
313 S. Washington Square, Lower Level
Lansing, Michigan 48933
(517) 487-1755 or 1-800-292-5923

WORKING ALTERNATIVES REFERENCES

Hines, Mary L., Director of Training, Michigan Protection and Advocacy Service for Developmentally Disabled Citizens, Inc., 313 S. Washington Square, Lower Level, Lansing, MI 48933.

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